

INSTITUTIONALIZATION AND ITS ALTERNATIVES FOR MENTALLY RETARDED PEOPLE IN THE UNITED STATES

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In the United States, "Amazingly little nationwide data [are] available from which [mental retardation] program trends can be extrapolated and implications drawn.. .decisions on the allocation of public resources are made by national and state policy-makers based on little more than the most rudimentary assumptions about what is actually happening in the field" (The President's Committee on Mental Retardation, 1976). Programming decisions on behalf of this nation's developmentally disabled need a firmer foundation in fact. As recently as ten years ago, that foundation might have been provided by focusing exclusively on institutionalized mentally retarded people; but that will no longer do. Using data that were complete only through 1971, Butterfield (1976)observed:

We can see now what we could not see then; 1967 was a watershed year. Until then, the number of residents in public facilities for the mentally retarded increased steadily. Since 1967, the number has decreased. . . . The decrease in residential census is not the result of a decrease in admissions. Neither is it the result of increased deaths. . . . A dramatic upturn in the rate of release from public institutions began in 1965. By 1971, more people were released than were admitted.... The question must be asked, are these released people faring better outside than they were inside the institution? The easy response is that they must be; look how terribly our institutions have been run. But the fact that one kind of program was bad, does not make another kind better....

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We have not yet begun to see clearly and directly how well extra-institutional placements are working.

The challenge now is to learn what is happening not only to institutionalized people but also to those increasingly large numbers who are being released from residential facilities. Precisely how many have been released or admitted recently is unknown. That is part of the dilemma service planners face. But in 1965, the number of mentally retarded people released from public residential facilities was only 7,000. In 1971, it was more than 17,000 (Mental retardation source book, 1972); 1971 is the last year for which nationwide data are available. For 1974, the National Association of Superintendents of Public Residential Facilities reported on the 81% of institutions for the mentally retarded that responded to a questionnaire. These 81% reported a 10% average decrease in resident population (Scheerenberger, 1975). Allowing for new admissions and readmissions indicates a much greater than 10% release rate during 1974. This suggests that the number of released residents still exceeds 17,000 per year, and there are no nationwide data on their fates. It is time to assess the human benefits (miseries?) of deinstitutionalization and to reassess the miseries (benefits?) of institutional living.

The Ideology of Deinstitutionalization

In its simplest terms, deinstitutionalization means the release of mentally retarded people from publicly financed residential facilities established for the care of people with any degree of mental retardation. The release may be to a resident's own home or to a foster home, nursing home, congregate care center, or community residential facility. The increasing number of such releases has been stimulated by court action (e.g., Wyatt v. Stickney, 1972), legislation such as U. S. Public Law 91-517, and advocacy groups such as the National Association for Retarded Citizens. All of these agents seem ideologically driven, the ideology being expressed in the "normalization principle." Nirje (1969) defined normalization as "making available to the mentally subnormal, patterns and conditions of everyday life which are as close as possible to the norms and patterns of everyday society" (P. 181). Nirje's definition is ambiguous with respect to whether "making

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available" refers only to placing mentally retarded people in more normal environments or whether it includes providing special clinical services and educational experiences to prepare them for more normal behavior. Wolfensberger (1972) reduced this ambiguity when he refined the definition to read "...utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (P. 28).

Part of the force of Wolfensberger's definition is that every mentally retarded person should live in the least restrictive possible normal environment and that each should receive preparatory and continuing services to promote behaviors that are as culturally normative as possible. These aspects of the normalization principle are humanitarian goals with which few disagree. Slightly more debatable is the notion that the means used to promote normal behavior should be as culturally typical as possible. How much variability is allowed by the qualification that the means shall be as typical as possible? Where shall the greatest value be laid, on the means or the end? Need all typical means be tried with each individual before any atypical means are applied to her or him? No consensus has been achieved on these matters, nor do we seem close to reaching one.

Even more debatable is the implication that no institution is normative enough for any retarded person, and that therefore we should close all institutions. What do those who argue for closing institutions mean by the term? "...the term institution refers to a deindividualizing residence in which retarded persons are congregated in numbers distinctly larger than might be found in a large family; in which they are highly regimented; in which the physical and social environment aims at a low common denominator; and in which all or most of the transactions of daily life are carried out under one roof, on one campus, or in a largely segregated fashion" (Wolfensberger, 1971. P. 15).

Nearly all publicly financed residential facilities in the United States house more than a hundred residents, and there is no serious question that the foregoing description aptly characterizes those facilities. Does the ideology of normalization require, therefore, that these facilities be closed? In principle it does not, but the pragmatics and economics of normalizing institutions are

so overwhelming that a consensus has arisen in this country that mildly and moderately retarded people should be housed outside such facilities. The rest of the debates are on whether any severely and profoundly retarded people should be cared for in institutions and whether the alternative arrangements are functionally different from the large institutions.

Institutions for Severely and
Profoundly Handicapped People?

The consensus of experts is that it will be 1990 at least before many severely and profoundly retarded people find community placements in the United States (Roos & Almore, 1976). The available data, which are limited, agree with the commonsense expectation that de institutionalization is proceeding much more rapidly for the mildly and moderately retarded than for the profoundly and severely retarded (Butterfield, 1976; Miller, 1976). On the level of practice, the judgment has been made: the severely and profoundly retarded of this country require institutional placement. Before considering that judgment, let us look at the historic trends, which put it in perspective.

National statistics allowed Butterfield (1976) to construct the following view of population movement in and out of U. S. residential facilities for the retarded between 1955 and 1971. Admission policies changed very little over this period. As far back as the records go, many more younger than older people were admitted. In 1955, 79% of all the mentally retarded admitted to an institution for the first time were under 20 years old. That figure has increased very little. What did change about 1965 were institutional release practices. Before 1965, residents were admitted as children, and they remained institutionalized at least until they were adults. When they reached adulthood, a few of the most capable were released, but most were retained in the institution. This resulted in increasing numbers of institutionalized retarded people of all ages, but particularly those under 20, since most of the newly admitted fell in that range. Institutionalized adults came mostly from the ranks of those admitted as children. From 1965 on, increasingly large numbers of adult residents were released. Initially these larger numbers were generally capable people who

could have been released in years gone by, but were not. Gradually, the more capable residents were discharged, and the less able adults were more and more often placed in the community. Recently this has meant more readmissions than in previous years, presumably because the released adults are less adequate and are failing more in their community placements.

Deinstitutionalization has begun in the United States, but it is proceeding conservatively. One facet of that conservatism is the judgment that severely and profoundly retarded people should have institutional care (Miller, 1975). The considerations upon which this judgment is based are varied (Wolfensberger, 1971). Some believe that the typical social and physical isolation of institutions allows more humane treatment of the retarded people whom society has rejected than would be possible in community-based facilities. It can be argued that all alternative ways of caring for severely and profoundly retarded people are more expensive. And there are those who find it unjustifiable to abandon the huge investment that has been made in our institutions. But the normalization principle argues that the most important consideration is whether more socially typical conditions promote more normative adjustment. Few data are available, but they seem to support the conservative approach to deinstitutionalization.

Miller (1975) examined mortality rates among the profoundly mentally retarded in order to assess the advisability of deinstitutionalizing them. His investigation focused on 3,384 people with IQs of less than 20 who were located in the far western states, mainly California. He examined mortality rates for the year 1973 and compared them according to placement — institutional, convalescent hospital, and other community settings. The rates were 19/1,000, 36/1,000, and 29/1,000, respectively, for the three settings. Concerning institutionalization, Miller concluded, "shifting the burden of care to other facilities does not cause any reduction in mortality and more likely increases it" (P. 8).

Although these data are consistent with the view that institutional care is more appropriate for profoundly retarded people than community-based care, not even the staunchest opponent of deinstitutionalization would hold that they are definitive. They cover a short interval in a few western states. They are restricted to a single dependent measure that, though important, does not speak

to the necessary range of considerations. But the main shortcoming of these data is that they do not provide information about the nature of the care provided: one cannot judge whether the institutional settings are less "normal" than the noninstitutional settings.

The very earliest comparative investigation of institutions showed that they differed from one another and that they had different effects on their residents (Butterfield & Zigler, 1965). These generalizations have been verified repeatedly (e.g., Balla, Butterfield, & Zigler, 1974; Klaber, 1970).² Noninstitutional placement settings also differ importantly (Bjaanes & Butler, 1974). The essential question is what sort of social environment and supportive services are provided in the institutional and noninstitutional facilities. Institutions have no corner on neglect; and with respect to the profoundly and severely retarded, there appear to be no investigations of institutional and community facilities that characterize the services offered in each so that rational evaluations can be made of both. The challenge is to perform evaluative research to inform judgment sensibly about whether to perpetuate the conservative approach to deinstitutionalizing severely and profoundly mentally retarded people.

Comparisons of Community-based and Institutional Programs

I have acknowledged above the commonly held view that mildly and moderately retarded people should be placed in community-based rather than institutional facilities. Though this consensus is based on ideological considerations, its wisdom will be evaluated empirically. In fact, the evaluations have begun. Nihira & Nihira (1975) and O'Connor (1976) have described community-based programs. Bjaanes & Butler (1974) and Landesman-Dwyer, Stein, & Sackett³ have compared different sorts of community-based programs, and Eyman, Silverstein, McLain, & Miller,⁴ institutional and noninstitutional programs.

One of the reasons given for institutional placement of mentally retarded people is to protect them and other citizens from jeopardies associated with the intellectual, emotional, and physical impairments of the retarded. If this is an important reason for

institutionalization, then community placement of previously institutionalized people might increase their jeopardy or that of the citizens in whose communities they are placed. Nihira & Nihira (1975) have begun the difficult task of evaluating the risks of community placement. They interviewed 80 caretakers of family care homes, 28 staff members of board and care homes, and 1 operator of a convalescent hospital, all in a single large California city. The respondents were asked to describe specific incidents illustrating problems confronted by the retarded people in their community facilities. Data were also collected on the age, sex, degree of retardation, and degree of physical handicap of the retarded person involved in each incident. The 109 interviews elicited 1,252 instances of problem behavior, of which 203 (16%) contained facts suggesting actual or potential jeopardy.

The 203 incidents were classified according to whether they contained jeopardy to (a) health and safety, (b) general welfare, or (c) the law. Jeopardy to health and safety occurred in 77% of the incidents and involved such things as faulty eating habits, violence, losing one's way, and sexual activities; jeopardy to general welfare occurred in 5%, and included behavioral regression and loss of verbal skills; jeopardy in the eyes of the law occurred in 18%, and consisted of such behaviors as making one's toilet in public, indecent exposure, sexual misconduct, violence, and theft. The incidents were also classified according to whom they jeopardized. The retarded citizens themselves were at risk in 79% of the incidents; their fellow residents, in 12%; and the general public, in 9%. Proportionately more of the incidents jeopardizing health and safety were contributed by the severely retarded than by the mildly or moderately retarded, whereas the latter two groups contributed proportionately more legal jeopardy.

This survey by Nihira & Nihira (1975) establishes that community-based placement does involve some risk to the health and safety of mentally retarded people and to the public. Whether these risks are greater than those associated with institutional placement is uncertain. How much greater the risks would have to be to justify institutional instead of community placement is problematic. It is also uncertain whether these risk rates are greater than those that would be observed for intellectually average people of comparable ages. Nor will it be easy to decide

whether institutional placement is justified if the community-based retarded are involved in more jeopardizing incidents than nonretarded people in the community. Though it would have been possible, Nihira & Nihira did not compare risk rates according to type of facility: family care, board and care, convalescent.

O'Connor (1976) has conducted the only national study of community residence, which she defined as

... a facility for the developmentally disabled which operates 24 hours a day to provide services to a small group of mentally retarded and/or otherwise developmentally disabled persons who are presently or potentially capable of functioning in the community with some degree of independence. These living facilities may also be known as group homes, hostels, boarding houses, and halfway houses. However, this definition does not include foster family placement typically serving five or fewer developmentally disabled individuals. Nor does it include nursing home services or other forms of care which are primarily directed toward meeting the health, health related, and/or medical needs of the resident. (P. 6)

She identified 611 facilities that fit this definition. Nearly half of these 611 were located in 6 states: Michigan (57), New York (52), Nebraska (48), California (47), Washington (46), and Minnesota (28). There were fewer than 8 facilities in 30 of the 50 states.

O'Connor classified the facilities as either "normalizing" or not by considering each of the following: (a) architecture of building; (b) security features such as high fences and bars on windows; (c) personal effects in sleeping area; (d) privacy in bath and bedrooms; (e) characteristics of furniture; and (f) judgment of general atmosphere and management of the facility. On the basis of a rigorous statistical test, she concluded that 69% of the facilities were normalizing, and 31% were not.

O'Connor further classified the 611 residences according to administrative type, size, and age of residents. She then sampled 105 facilities and conducted intensive interviews in each of them. A wealth of information resulted. The following are only highlights:

The most common community residential facility (CRF) was a large older home in a residential or combined residential and business area, located within walking distance of grocery stores and other shops. Over two-thirds of the facilities were considered "normalized." However, since normalization of the facility

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was related to facility size, over one-half of the residents were living in "nonnormalized" facilities. Community opposition, mostly by neighbors, at the time of development was faced by about one-third of the facilities; attitudes were reported to have improved because of the residents' behavior and staff efforts.

There were two primary staffing patterns: (a) full-time administrators and direct-care staff, principally in large facilities and those serving children; and (b) houseparents, most common in small facilities and those serving older residents. The average staff-to-resident ratio was 0.52, or one staff person for every two residents. This ratio was higher for children and adolescents, and lower for adults. Primary causes of staff turnover were low pay, long hours of responsibility, and little privacy, especially for live-in staff.

Virtually all facilities used one or more types of community services; the most satisfaction was expressed with religious, medical, and dental services. Transportation was the most needed, but inadequate or unavailable, community service. Ninety percent of the residents lived in facilities reporting a need for 1 or more of 15 types of community services; nearly one-half were living in facilities in need of 4 or more services. One-third of the facilities reported a need for educational services and vocational training.

Residents ranged in age from very young to very old, although most were between 17 and 34 years of age. Most residents had basic self-help skills, and 80% were estimated to have an IQ of 40 or above. Over one-half of the residents had moved to the CRF directly from an institution, and an additional 10% had a history of institutionalization. For those residents with a history of institutionalization, the median length of stay in the institution had been 10 years; 25% of them had lived in an institution for 30 years or more.

Two-thirds of the residents had periodically reviewed developmental plans, although the content and complexity of the plan varied considerably. Of the residents, 14% had paid jobs in the community; 43% were in work training programs; 26% were in sheltered workshops; 47% were attending some school classes; 31% attended school as their principal program; 8% were in nonvocational activity centers and/or on-grounds training; 4% were not reported to be in programs or receiving any skill training. Most residents

had home responsibilities. The proportion of residents having a household task decreased as the complexity of the task increased; only 7% of the residents, i.e., the young or severely disabled, had no responsibilities in the home.

The most popular community activities were visiting restaurants and snack bars, shopping, and recreation, both indoor and outdoor. One-half of the residents had regular contact with their families. Fifty-seven percent had friends outside the facility whom they both visited and entertained as guests. One-fifth of the residents dated. Facility managers felt that four of every ten residents would be able to live independently in the community in the future.

These results put the question of jeopardy, addressed by Nihira & Nihira (1975), into some perspective. There are clearly positive features to community placement, and these must be weighed against the risks. What seems called for are investigations of alternative institutional and noninstitutional arrangements combining procedures such as those employed by O'Connor and the Nihiras.

O'Connor's results strongly suggest that there are important qualitative differences among community residential facilities. This suggestion is supported by the findings of Bjaanes & Butler (1974) and Landesman-Dwyer and co-workers. The latter study is much more extensive, though it is confined to a single state.

The State of Washington has embarked on a major program of placing mentally retarded people in group homes that are privately owned and operated and serve from 6 to 20 residents each. Landesman-Dwyer and co-workers observed the activities of 400 residents of 23 such homes. The residents were a diverse group, including both children and adults, the severely and profoundly retarded and the mildly and moderately retarded, and the previously institutionalized and those who had never been in an institution. Each resident was observed for 40 hours. This truly heroic set of observations merits careful study. Here are only a few of the findings:

There was more positive social interaction among residents of the larger facilities. Residents whose families visited more often exhibited less independent behavior. Those in facilities designed explicitly as group homes went into the community less often than residents of converted houses. The more homogeneous the levels of retardation among the residents, the more positive social be-

haviors they exhibited. I have emphasized these findings because they run counter to the usual expectations, thus highlighting the need for systematic evaluation of noninstitutional placements. Many of the findings of Landesman-Dwyer and co-workers are not so surprising; they show that no community program is appropriate for all mentally retarded people.

Eyman and associates⁶ seem the only investigators who have risen to the complex challenges of evaluating the impact of both institutional and noninstitutional arrangements on the development of mentally retarded people. Those challenges are formidable. The research must be longitudinal, since the only way to evaluate the impact of a programming environment is to monitor the development of residents who have experienced it for some time. Different programming environments serve different sorts of people. Thus, there are now few mildly retarded people in institutions, and the more severely retarded who are in community settings tend to be placed in convalescent homes rather than group homes. Consequently, comparing across types of facility requires complex statistical corrections of the longitudinal change scores. To be revealing, the comparisons must involve several sorts of behavioral measures, including the various aspects of adaptive behavior and social and emotional behavior as well. Moreover, the characteristics of the programs offered and of the environments in which they are offered must be quantified. Eyman and associates have made important advances toward solving these problems, though there is still a long way to go.

These investigators measured changes over a three-year period in personal self-sufficiency, community self-sufficiency, and personal-social responsibility. They studied people in two institutions, convalescent hospitals, and other community facilities. They quantified the characteristics of the treatment environment in each of the facilities studied and made extensive statistical corrections for differences in mental level among the residents of the various facilities. They found that the characteristics of the treatment environments accounted for substantial amounts of the variance in change on their three kinds of adaptive behavior, regardless of the nature of the facility. Over-all, foster-care and board-and-care facilities promoted the most positive change in adaptive behavior, and the less severely handicapped residents

developed most positively. As with other data on community placements, these findings emphasize the importance of considering each facility on its own merits rather than generalizing about types of alternatives to institutional programming.

Conclusions

Because deinstitutionalization is a recent trend in the United States, we cannot yet see how well it is doing. The available evidence suggests that community-based programs are heterogeneous. Some are producing distinctly more positive outcomes than others. The data allow the inference that some institutional programs are serving the mentally retarded better than some community programs. The time is past when we can paint either sort of treatment program completely black or completely white.

The challenge for the future is to specify client needs clearly and to define the best ways to meet them. The distinction between institutional and community programs is relevant to this endeavor. For the foreseeable future, the question is not which sort of program is better, but rather, the precise nature of the various programs. In all likelihood, the conservative approach of deinstitutionalizing the ablest residents first will continue; but that should be taken as an indication that programming decisions have yet to find a solid factual base.

Research like that of O'Connor (1976), Eyman and associates,⁷ and Landesman-Dwyer and co-workers⁸ is improving the situation; but as the last group has correctly observed, we now need studies that are prospective, broadly comparative, and partially experimental. Program planners need prospective studies that examine clients over time in several different settings. They need broadly comparative studies that capture the range of programming alternatives in both institutional and noninstitutional arrangements. And they need to see the effects of deliberately manipulating environmental variables that seem critical in successful programs. So far, the movement to small community-based facilities is like a large, poorly controlled experiment, guided by worthy intentions and complex economic considerations. It is time for a more systematic approach that includes objective assessment of outcomes.

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NOTES

¹See also R. K. Eyman, A. B. Silverstein, R. E. McLain, & C.R. Miller (1976) Effects of residential settings on development. Washington, D.C.: Fourth Congress of the International Association for the Scientific Study of Mental Deficiency.

²Ibid.

³S. Landesman-Dwyer, J. G. Stein, & G. P. Sackett (1976) A behavioral and ecological study of group homes. Paper presented at NICHD Conference on the Application of Observational/Ethological Methods to the Study of Mental Retardation. University of Washington, Lake Wilderness Conference Center, June 1976.

⁴Eyman et al., op. cit.

⁵Landesman-Dwyer et al., op. cit.

⁶Eyman et al., op. cit.

⁷Ibid.

⁸Landesman-Dwyer et al., op. cit.

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